
Welcome to FH Europe Foundation's September 2024 edition of Heart Beat.



FH Europe Foundation
The European Familial Hyperlipidaemias Foundation

Heart Beat News

FH Europe Foundation September 2024 Heart Beat Newsletter

Welcome to the September edition of our Heart Beat Newsletter!

This month has been particularly special as we celebrated FH Awareness Day with a dynamic campaign that culminated in an engaging webinar. We're thrilled to share that our FH AWD hashtags and visuals reached audiences worldwide, thanks to our incredible network and partners who amplified our messages.

Together, we successfully raised awareness about familial hypercholesterolaemia!

In addition to our awareness efforts, we hosted two enlightening webinars from our HoFH Webinar Trilogy, and we invite you to join the final session today!

In this edition, you can look forward to insights on World Heart Day and learn how to support the World Heart Federation's first global petition prioritising heart health. We also cover significant topics such as World Patient Safety Day, Apheresis Day, and EnprEMA's cross-border paediatric trials. You'll find updates from our network in Croatia, Czechia, Ireland, and the UK, as well as news from Germany, Australia, and North Macedonia. We've included essential updates from our partners and a variety of new publications that are vital for our community.

Enjoy the read and have a wonderful weekend ahead!



FH EUROPE FOUNDATION
NEWS



FH Awareness Day 2024 – A Day of Engagement and Advocacy

On and around 24 September, FH Awareness Day brought together a vibrant array of activities from our Network members and communities worldwide, all aimed at raising awareness of familial hypercholesterolaemia (FH). From scientific talks, patient testimonies and city runs, to free testing opportunities, TV news features, and the launch of mobile labs for screening cardiovascular risk factors, there were numerous ways for the public to get involved.

This year, the FH Europe Foundation's campaign theme, Prevent the Preventable, focused on three key objectives: educating the public on the difference between high cholesterol and FH, promoting early FH screening through the PERFECTO and PerMed FH projects, and advocating for a comprehensive cardiovascular health (CVH) plan for Europe. You can read the official press release [here](#).

To support the campaign, a toolkit was created that included short social media videos featuring key messages about cholesterol, FH, and the impact of the disorder. These materials were translated into multiple languages and shared widely by network members and supporters. Many individuals and organizations also showed their support by using the "I Support FH Awareness Day" frame on social media platforms.

In addition, two special recordings were produced in collaboration with international researchers, including Prof. Mafalda Bourbon, Dr Simon Pfisterer, Dr Amany Elshorbagy, and patient ambassadors. These covered two important topics:

- [*Understanding the Differences Between High Cholesterol and Familial Hypercholesterolaemia*](#)
- [*Understanding the Connection Between Obesity, Diabetes, and Familial Hypercholesterolaemia*](#)

A dedicated webinar, ***The Importance of FH Screening in the Context of the CVH Plan***, was also held, highlighting the successes, challenges, and learnings from Norway, where FH cascade screening programme including genetic testing has led to detecting over 40% of the affected population and going strong. The panellists also shared the findings from 2 surveys conducted among patients and the general public in Cyprus and Romania, unmasking new insights into the barriers and opportunities to implementing FH screening. If you missed the live event, the recording will be available shortly and we encourage you to share it within your networks to keep the conversation alive.

We would like to extend our heartfelt thanks to everyone who contributed to this truly global collaborative effort. Together, we can *Prevent the Preventable!*

Learn more about [here](#).



World Heart Day 2024: A Global Call for Cardiovascular Health

Cardiovascular disease remains the leading cause of death in Europe and worldwide in 2024, underscoring the critical need for national cardiovascular health plans. Despite this urgent reality, many countries still lack effective policies to combat heart disease. While the role of high-level decision-makers is crucial, each of us can contribute to driving change.

On Sunday, 29 September, the world will unite to celebrate World Heart Day. In solidarity with the World Heart Federation (WHF), we call on global leaders to take decisive action against this pressing public health issue. In line with the European Alliance for Cardiovascular Health's (EACH) ongoing efforts to establish both European and national Cardiovascular Health (CVH) Plans, the WHF has launched a historic global petition urging governments to prioritize heart health.

By signing this petition, you can help advocate for stronger measures to prevent heart attacks, strokes, and other cardiovascular diseases—actions that have the potential to save millions of lives.

FHEF has already added its voice. Have you?

Use your heart and say YES to robust health policies. Let's work together to prevent the preventable. Add your voice today!

For more information and to sign the petition, visit the [World Heart Federation Global Petition](#). Once you've signed, create and share a personalized poster and testimony about your commitment to heart health. Learn more and get started [here](#).

JOIN US!

MODERATED BY
CHYREL LICHAA
AND PROF. ALBERT
WIEGMAN

**The recent trio of treatments in HoFH:
PCSK9 inhibitors, lomitapide and evinacumab**

THURSDAY, 26 SEPTEMBER, 18.00 CEST

PROF. LUIS MASANA
DR. ANTONIO GALLO
PROF. RAUL SANTONS
MARIA NASSIF
MARWA SADIK

HoFH
AWARENESS DAY

FH Europe
Foundation

Join the Final Webinar in the HoFH Treatment Trilogy

The HoFH webinar series has been a key part of our extended HoFH Awareness Day campaign, offering essential insights into the evolving landscape of HoFH treatment. The first session explored genetics and gene therapy, while the second focused on gold-standard treatments like statins, ezetimibe, and apheresis. These sessions showcased real-life evidence and

featured incredibly rich and informative exchanges between medical experts and patient advocates, bridging the gap between science, patient experiences, and healthcare professionals.

Recordings of the first two webinars will be available soon. Due to the overwhelming number of thoughtful questions from participants, FHEF has committed to developing a special document that will capture all questions and answers from the three webinars, to be shared shortly.

Don't miss the final session tonight, where cutting-edge therapies like PCSK9 inhibitors, lomitapide, and evinacumab will take centre stage!

Register [here](#).



“Get it right, make it safe!” - why World Patient Safety and Apheresis Awareness Days are important for patients living with HoFH

On 17 September 2024, we marked Apheresis Awareness Day alongside World Patient Safety Day, both vital for individuals and families affected by inherited hyperlipidaemia, particularly Homozygous Familial Hypercholesterolaemia (HoFH). This year's theme, “Improving diagnosis for patient safety,” highlighted the critical role of accurate diagnosis in enhancing health outcomes.

Apheresis is a vital, life-saving procedure for many HoFH patients, helping to manage cholesterol levels and prevent cardiovascular complications. However, its effectiveness hinges on safe and correct treatment protocols. Elsie Evans, FH Europe Foundation Ambassador Program Manager and a lifelong HoFH patient, highlighted how these observances remind us of the importance of early detection, individualised care, and safe treatment practices.

As we reflect on these important days, visit our website and listen to messages from **Penilla Gunther, President of the European Patient Safety Foundation and an Expert in the Cancer Mission Board, appointed by the European Commission and two HoFH Patient Ambassadors – Maria Nassif and**

Thanos Pallidis, advocating for patient safety, correct diagnosis in the context of HoFH and apheresis.

Read more about it and listen to the messages [here](#).

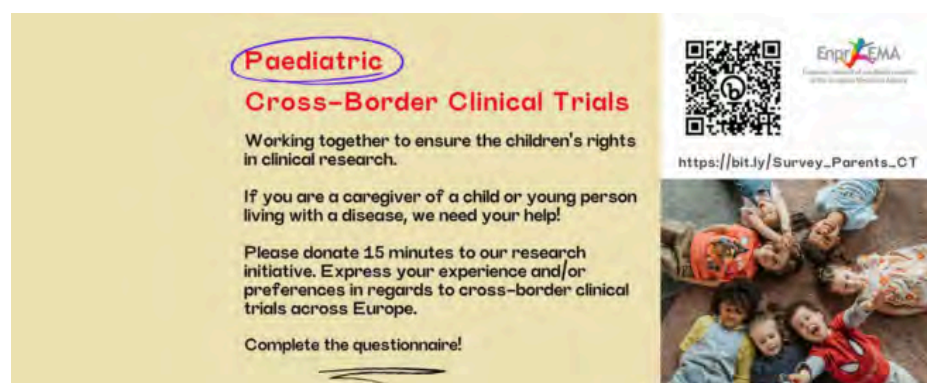
Could Prevention Be an Intervention in Cardiology?

On 11 October, Magdalena Daccord, CEO of FHEF, will speak at an international conference in Warsaw, Poland, titled Prevention & Intervention—where preventive cardiology meets interventional cardiology. The event focuses on lifetime cardiovascular risk and disease management for all ages.

A key session will feature healthcare institutions and patient organisations discussing comprehensive approaches to cardiovascular health, including prevention, modern diagnostics, and treatment advancements. It will highlight patient-centred care, emphasising collaboration between patients and medical teams for better health outcomes and the role of prevention as a critical intervention.

On the speaker panel, she will be joined by Senator Agnieszka Gorgoń-Komor, Dr Marta Kałużna-Oleksy, Dr Izabella Uchmanowicz, and Agnieszka Wolczenko, leader of EcoSerce, the Polish Member organisation of the FHEF Network.

Read more about it [here](#).



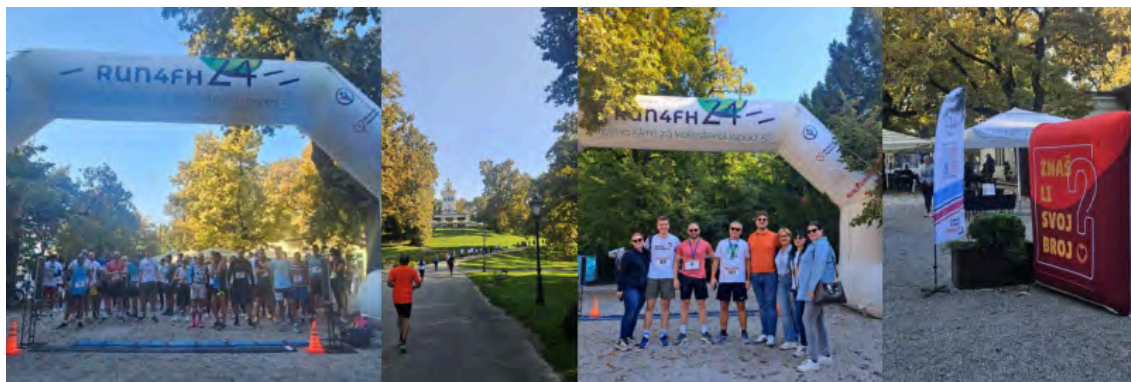
Help Shape Cross-Border Paediatric Clinical Trials in Europe

FH Europe Foundation is delighted to invite you to discover the groundbreaking initiative in the space of paediatric cross-boarded clinical trials.

The Cross-Border Access to Paediatric Clinical Trials Working Group, established by the European Network of Paediatric Research at the EMA (Enpr-

EMA), aims to facilitate children's inclusion in clinical trials across Europe by overcoming language barriers. The group is collecting data from Clinical Research Units and parents to understand current challenges in cross-border trials. If you are a parent of a parent who could contribute to this intimate, please consider giving 12–15 minutes of your time to respond to the survey, which will help create future guidance to ensure language is not a barrier for children and young people accessing clinical trials.

We're inviting you to complete the survey [here](#).



Croatia - Croatian Dyslipidaemia Patient Organisation

Run4FH Croatia: A Successful Movement!

On Sunday, 22 September, the Croatian Dyslipidaemia Patient Organisation, in collaboration with RunCroatia, the Croatian Society for Atherosclerosis, the Croatian Hypertension League, and FH Europe Foundation, successfully hosted Run4FH24—an event dedicated to promoting physical activity and raising awareness about high cholesterol, including genetic conditions like HeFH and HoFH. A total of 150 runners participated in the 5 km race at Maksimir Park in Zagreb, running under the slogan "Run 5 km for Cholesterol Lower than 5 mmol/l." Run4FH has become a movement in the country as similar runs are scheduled across different cities and towns, improving health literacy and promoting outdoor physical activity.

Prepared by Croatian Dyslipidaemia Patient Organisation



Czech Republic - ČAKO

Raising Awareness of FH and elevated Lp(a) in the country

Despite efforts, awareness of Familial Hypercholesterolaemia (FH) and elevated Lipoprotein(a) [Lp(a)] remains low in the Czech Republic. As part of the 9th FH Week, ČAKO conducted LDL cholesterol measurements across various cities and measured levels of Lp(a) at one hospital. The results were significant, demonstrating the value of preventive health measures in this area.

In total, samples from 78 individuals were analysed, revealing risk values greater than 120 nmol/l in 15 to 16 participants, which aligns with the reported prevalence of 20% in the population. As follow up to the campaign, medical professionals will reach out to the diagnosed patients for further evaluation and care. Notably, two young women exhibited extremely high Lp(a) levels of 364 nmol/l (40 years) and 423 nmol/l (36 years). Additionally, four suspected cases of HeFH were identified during this initiative.

Given the evident lack of awareness surrounding FH and elevated Lp(a) among the general public, ČAKO held a press conference on FH Awareness Day, 24 September, titled “Inherited High Cholesterol: A Real Threat.”

Prepared by ČAKO



Ireland – Croí

Heartfest 2024 in Galway

Heartfest 2024, a three-day celebration of cardiovascular health hosted by Croí, the Heart and Stroke Charity, taking place at Eyre Square, Galway, from 25-27 September. The event, coinciding with FH Awareness Day and World Heart Day, promotes global heart health advocacy. Visitors can benefit from free blood pressure, cholesterol, and pulse checks, provided by the Croí Mobile Health Hub, Ireland's largest mobile stroke and heart disease detection unit. Croí's expert multidisciplinary health team is offering advice, and attendees have the opportunity to participate in the "Irish Hearts" research project, contributing to vital family heart health research.

Read more about it [here](#).

Prepared by Croí



Singapore – FHCARE Singapore

Special Seminar on FH Awareness in Singapore

Today, Singapore is hosting a special seminar focused on raising awareness about Familial Hypercholesterolemia (FH). The event has attracted significant interest, with 250 registrants, primarily healthcare professionals, including nurses and doctors.

Ahead of the seminar, participants were invited to complete a quiz on FH, with 170 responding. Impressively, 85 participants answered all five questions correctly, showing strong knowledge of the condition.

Later this year, more activities will be organised for people with FH, alongside engagement sessions with general practitioners.

Prepared by FHCARE Singapore

Urgent global action is required to improve the screening, diagnosis and treatment journey for women with cardiovascular disease

 [Read now!](#)



 Global Heart Hub

Global Heart Hub

Women and Heart Report Highlights Late, Missed, and Misdiagnosis of Heart Disease in Women

The Global Heart Hub has released its Women and Heart Report, which examines the issues of late, missed, and misdiagnosis of heart disease in women. This release coincided with a patient-led roundtable discussion involving 27 participants from 15 countries, including women with lived experience, patient organisation leaders, public health experts, researchers, and clinicians. The roundtable highlighted the under-representation of women in clinical trials, and the lack of research on female-specific risk factors, and identified four priority areas: healthcare system and medical education, research, patient engagement and awareness, and policy change. These will guide efforts to improve diagnosis and treatment for women with cardiovascular disease.

Read more about it [here](#).

Prepared by Global Heart Hub

NEWS
FROM AROUND THE WORLD

FH Australia

Free Lecture on Cholesterol and Heart Health

The newly established patient support group in Australia - FH Australia, in collaboration with Dr Nick Lan, a cardiologist at Fiona Stanley Hospital and Clinical Senior Lecturer at The University of Western Australia, offered to the public a free lecture about cholesterol. On the occasion of FH Awareness Day, the speaker discusses how cholesterol impacts heart health and tips for maintaining a healthy heart. Dr Lan specialises in preventive cardiology and has published over 60 medical articles and a book chapter on cholesterol and diabetes.

The Fiona Wood Public Lecture Series is a free event. Learn more about it [here](#).

Germany

Free FH Testing for Children in Hannover

In celebration of FH Awareness Day, the Vroni Team, in collaboration with **Prof. Dr Kordonouri**, organised a free testing event for Familial Hypercholesterolaemia (FH) at the Children and Teenager Hospital Auf der Bult in Hannover. This initiative was open to children aged 5 to 14 years, emphasising the importance of early detection and intervention.

This event was part of the larger **VRONI project**, which aims to raise awareness and improve screening for FH among young populations since its expansion from Munich/Bayern to other regions.

Kazakhstan

The Kazakhstan Atherosclerosis Society, reached out to FHEF to share about the efforts to make the FH Awareness Day 2024 an informative and engaging campaign in Kazakhstan.

As part of the series of events online and offline, the society team organised an Open House, offering testing opportunities, conducted public outreach activities, and disseminated information regarding heterozygous and homozygous FH through social media and mass media channels.

Please take a moment to visit the [Kazakhstan Atherosclerosis Society on social media](#) and support their innovative awareness campaign with a "like."

North Macedonia

Championing Awareness for Familial Hypercholesterolemia in North Macedonia

North Macedonia is making waves in the fight against Familial Hypercholesterolemia (FH)! On 12 September 2024, the academic and professional communities united to spotlight this crucial health issue at an inspiring symposium titled "**Familial Hypercholesterolaemia versus Hypercholesterolemia—The Most Common Rare Disease.**"

Hosted by the Macedonian Association of Cardiology in collaboration with the Faculty of Medicine at the University of St. Cyril and Methodius in Skopje and the Macedonian Academy of Sciences and Arts, the event took place in the vibrant amphitheatre of the Faculty of Medicine. It kicked off with a warm welcome from **Prof. Dr Jorgo Kostov**, the President of the Macedonian Cardiology Association, setting the stage for an engaging day of knowledge sharing.

The symposium featured a lineup of esteemed speakers who delivered valuable insights. **Academic Prof. Dr Sashko Kedev** opened the discussions with a deep dive into the risk factors associated with cardiovascular diseases. He was followed by **Prof. Dr Maria Vavloukis**, who brilliantly outlined the differences between familial hypercholesterolaemia and general hypercholesterolaemia, shedding light on the nuances of these conditions. The discussions culminated with **Ass. Prof. Sanja Kiprianovska**, who shared groundbreaking insights on genetic profiling for FH.

The symposium not only aimed to enhance understanding and awareness of familial hypercholesterolaemia but also underscored the vital role of education and research in combating this prevalent yet often overlooked condition, which is wrongly considered as rare.

Poland

Raising Awareness about Familial Hypercholesterolemia (FH)

On 22 September in Katowice, a patient advocate shared her and her family's experience of living with Familial Hypercholesterolemia (FH) at the Polish Cardiac Society congress, alongside Professor Marlena Broncel and Dr Paulina Gorzelak-Pabiś from a reference centre in Central Poland.

With FH Awareness Day occurring just five days before World Heart Day, this event provided an excellent opportunity to discuss FH in the context of premature heart disease and prevention.

This effort to raise awareness among the public at a national society event exemplifies the power of collaboration in addressing important health issues.

Portugal

The Portuguese FH Study, led by Prof. Mafalda Bourbon, our very own advisor, celebrates its **25th anniversary**. To commemorate this very special

occasion, a special education event will take place on 27 and 28 September in Cascais, next to Lisbon.

Among guest speakers will be Magdalena Daccord, CEO of FHEF presenting on the Prague Declaration and the need to screen early for FH and the Ambassadors Programme, encouraging more patients to actively participate in advocacy in Portugal and showcasing the role of clinicians in the process.

Other speakers will include Prof. Albert Wiegman from the Netherlands and FHEF's Trustee and Prof. Olga Kordonouri from Germany, leading the VRONI programme in Hamburg.

Slovenia

September is the Newborn Screening Awareness Month. On 25 September, the **"Ljubljana 2024 Genomics in Newborn Screening Workshop"** was hosted by the University of Ljubljana—Faculty of Medicine with Prof. Urh Groseelj, FHEF's scientific advisor, in collaboration with the International Society for Neonatal Screening (ISNS).

This workshop, limited to 40 international participants, focused on the latest advancements and the ethical, legal, and social implications (ELSI) of genomics in newborn screening. Attendees were able to join plenary lectures, hands-on workshops, and case studies, fostering discussion and networking opportunities with global experts.

The topic becomes increasingly relevant to the familial hyperlipidaemias' community as pilot projects in newborn screening for FH are currently running in Czechia, Germany, Norway, and Slovenia.

Learn more about it [here](#).

PARTNER
NEWS



EURORDIS

Applications Now Open for 2025 EURORDIS Open Academy Schools

EURORDIS – Rare Diseases Europe has opened applications for the 2025 Open Academy Schools, a newly revamped program under the European Rare Diseases Research Alliance (ERDERA). The schools, held in Barcelona from 2-5 June, 2025, will offer patient advocates and researchers a focused four-day training on Medicines Research & Development and Scientific Innovation & Translational Research. A new online course, "Navigating Rare Disease Research: Data, Ethics, and AI in Europe," will run from January to June 2025. These initiatives aim to equip advocates with skills to influence rare disease policy and research across Europe. Apply now to participate in this transformative experience. Don't forget to select FH Europe Foundation as your organisation when applying, if you are our member!

Read more about it [here](#).

EURORDIS Urges Greater Focus on Rare Diseases in EU Health Mandate

On 17 September 2024, European Commission President Ursula von der Leyen introduced her team of nominated Commissioners, including Olivér Várhelyi for Health and Animal Welfare. EURORDIS has welcomed the health focus but emphasised the need for rare diseases to be prioritised in the new mandate. While the mandate highlights key health reforms, EURORDIS calls for an EU Action Plan on Rare Diseases to ensure coordinated efforts, better access to treatments, and improved patient outcomes across Member States.

Read more about it [here](#).

How Newborn Screening is Transforming Lives in Ukraine

Despite the challenges of war, Ukraine's newborn screening program remains vital, offering early detection of rare diseases. As of April 2023, the program expanded from screening for just 4 conditions to 21, providing more families the opportunity for early diagnosis and life-saving care. Early detection allows timely treatment, significantly improving the quality of life for affected children.

EURORDIS continues to advocate for a harmonised approach to newborn screening across Europe. Disparities in access and policies leave many

children without early diagnoses. EURORDIS promotes 11 Key Principles to ensure every newborn in Europe receives the best possible chance for early detection and care, regardless of where they are born.

Read more about it [here](#).

European Alliance for Cardiovascular Health - EACH EACH Partners Urge European Commission to Uphold Promise of Action on Cardiovascular Disease

EACH Partners, including FH Europe Foundation, have written to European Commission President Ursula von der Leyen, urging her to uphold her commitment to addressing cardiovascular disease (CVD) in Europe. With CVD being the continent's leading cause of death, the letter highlights the need for a specific EU Cardiovascular Health Plan, building on the success of the Beating Cancer Plan. While the Healthier Together initiative is a good start, the partners stress that comprehensive action is necessary to combat CVD and its related conditions like hypertension and diabetes. Support from Member States and the European Parliament is strong, and the letter calls on the Commission to ensure cardiovascular health remains a top priority in the upcoming mandate.

Read the full letter [here](#).

European Patients' Forum World Patient Safety Day 2024: Focus on Improving Diagnosis for Safer Healthcare

On 17 September, World Patient Safety Day highlights the global call for patient safety as a health priority. This year, the theme set by WHO is "Improving diagnosis for patient safety: Get it right, make it safe!" Diagnostic errors account for 16% of preventable harm in healthcare. Challenges such as healthcare inequalities, workforce shortages, and lack of patient-centred systems contribute to these errors. Solutions include enhancing healthcare resilience, investing in health literacy, and leveraging technology like AI for accurate diagnoses. The aim is to build more resilient, equitable healthcare systems, ensuring safer care for all.

Read more about it [here](#).

Sex Differences in Familial Hypercholesterolaemia Treatment

We are excited to share two important new publications by Dr Raul D. Santos that explore treatment differences in familial hypercholesterolaemia (FH) across different populations.

- [Sex Differences in Treatment of Familial Hypercholesterolaemia: A Meta-Analysis](#)

This meta-analysis examines disparities in FH treatment between men and women. Despite FH being equally prevalent in both sexes, women tend to be diagnosed later, receive less aggressive treatment, and are less likely to meet recommended LDL cholesterol targets. The study underscores how sex differences can impact clinical presentation and response to lipid-lowering therapies (LLTs), advocating for updated clinical guidelines to ensure that both men and women receive appropriate care.

- [Familial Hypercholesterolaemia: Need for Equitable Treatment in Women and Men](#)

These two publications are crucial for advancing the conversation on equitable treatment of FH. Dr Santos also discussed these findings on the European Society of Cardiology's Cardio Talk which you can listen to [here](#).

Lipoprotein(a) and Cardiovascular Disease by Prof. Børge G. Nordestgaard and Anne Langsted

We are excited to highlight a new publication in The Lancet, exploring the impact of elevated lipoprotein(a) on cardiovascular disease and aortic valve stenosis. The study reveals that one in five people globally are at high risk due to high lipoprotein(a) concentrations, which are largely genetically determined. It discusses global variations in levels, gender differences, and the need for lifetime measurement of lipoprotein(a) to better manage cardiovascular risk. With promising new drugs in development, this comprehensive review addresses lipoprotein(a)'s role in familial hypercholesterolaemia, diabetes, and future treatment options.

We are delighted to share a link with the permission of the author to the full publication [here](#).

Health Technology Assessment for Gene-Silencing Therapies for Lowering Lipoprotein(a) in Coronary

Heart Disease

A recent study, led by Dr Angela Burvill, Professor Gerald F. Watts, Dr Richard Norman, and Prof. Zanfina Ademi, evaluates the potential of gene-silencing therapies to lower lipoprotein(a) [Lp(a)] in the secondary prevention of coronary heart disease (CHD). The research focuses on two investigational therapies, administered either monthly or every three months. Olpasiran and pelacarsen are gene-silencing therapies that lower Lp(a) levels ranging from 65-98%. Cardiovascular outcome trials are ongoing. Mendelian randomisation studies estimated clinical benefits from Lp(a) levels lowering.

The study estimated the cost-effectiveness of these therapies within the Australian healthcare system. A therapy administered every three months was found to be cost-effective at an annual price of AU\$1,867, while the monthly therapy was cost-effective at AU\$984. These therapies offer a promising option for reducing recurrent CHD events, particularly in high-risk individuals.

Read more about it [here](#).

**SAVE
THE DATE**

- **TODAY** - The recent trio of treatments in HoFH: PCSK9 inhibitor, lomitapide and evinacumab
- **29 September** - World Heart Day
- **1 November** - FCS Awareness Day
- **8 - 10 November** - FHEF Annual Network Meeting 2024
- **16-18 November** - American Heart Association Conference
- **4-6 December** - International Symposium on Atherosclerosis

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